

106TH CONGRESS
1ST SESSION

H. R. 762

To amend the Public Health Service Act to provide for research and services
with respect to lupus.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 12, 1999

Mrs. MEEK of Florida (for herself, Ms. ROS-LEHTINEN, Ms. PELOSI, Mr. COOK, Mr. CLAY, Mrs. THURMAN, Ms. JACKSON-LEE of Texas, Mr. BONIOR, Mr. MEEKS of New York, Mr. GOODE, Mr. PASTOR, Mr. DEFazio, Mrs. MINK of Hawaii, Mr. HOLDEN, Mr. QUINN, Mr. SHOWS, Ms. KILPATRICK, Mr. GREEN of Texas, Mr. FILNER, Mr. BLAGOJEVICH, Mr. SERRANO, Mr. MORAN of Kansas, and Mr. BALDACCI) introduced the following bill; which was referred to the Committee on Commerce

A BILL

To amend the Public Health Service Act to provide for
research and services with respect to lupus.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Lupus Research and
5 Care Amendments of 1999”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds that—

1 (1) lupus is a serious, complex, inflammatory,
2 autoimmune disease of particular concern to women;

3 (2) lupus affects women 9 times more often
4 than men;

5 (3) there are 3 main types of lupus: systemic
6 lupus, a serious form of the disease that affects
7 many parts of the body; discoid lupus, a form of the
8 disease that affects mainly the skin; and drug-in-
9 duced lupus caused by certain medications;

10 (4) lupus can be fatal if not detected and treat-
11 ed early;

12 (5) the disease can simultaneously affect var-
13 ious areas of the body, such as the skin, joints, kid-
14 neys, and brain, and can be difficult to diagnose be-
15 cause the symptoms of lupus are similar to those of
16 many other diseases;

17 (6) lupus disproportionately affects African-
18 American women, as the prevalence of the disease
19 among such women is 3 times the prevalence among
20 white women, and an estimated 1 in 250 African-
21 American women between the ages of 15 and 65 de-
22 velops the disease;

23 (7) it has been estimated that between
24 1,400,000 and 2,000,000 Americans have been diag-

1 nosed with the disease, and that many more have
2 undiagnosed cases;

3 (8) current treatments for the disease can be
4 effective, but may lead to damaging side effects;

5 (9) many victims of the disease suffer debilitat-
6 ing pain and fatigue, making it difficult to maintain
7 employment and lead normal lives; and

8 (10) in fiscal year 1996, the amount allocated
9 by the National Institutes of Health for research on
10 lupus was \$33,000,000, which is less than $\frac{1}{2}$ of 1
11 percent of the budget for such Institutes.

12 **TITLE I—RESEARCH ON LUPUS**

13 **SEC. 101. EXPANSION AND INTENSIFICATION OF ACTIVI-** 14 **TIES.**

15 Subpart 4 of part C of title IV of the Public Health
16 Service Act (42 U.S.C. 285d et seq.) is amended by insert-
17 ing after section 441 the following section:

18 “LUPUS

19 “SEC. 441A. (a) IN GENERAL.—The Director of the
20 Institute shall expand and intensify research and related
21 activities of the Institute with respect to lupus.

22 “(b) COORDINATION WITH OTHER INSTITUTES.—
23 The Director of the Institute shall coordinate the activities
24 of the Director under subsection (a) with similar activities
25 conducted by the other national research institutes and
26 agencies of the National Institutes of Health to the extent

1 that such Institutes and agencies have responsibilities that
2 are related to lupus.

3 “(c) PROGRAMS FOR LUPUS.—In carrying out sub-
4 section (a), the Director of the Institute shall conduct or
5 support research to expand the understanding of the
6 causes of, and to find a cure for, lupus. Activities under
7 such subsection shall include conducting and supporting
8 the following:

9 “(1) Research to determine the reasons under-
10 lying the elevated prevalence of lupus in women, in-
11 cluding African-American women.

12 “(2) Basic research concerning the etiology and
13 causes of the disease.

14 “(3) Epidemiological studies to address the fre-
15 quency and natural history of the disease and the
16 differences among the sexes and among racial and
17 ethnic groups with respect to the disease.

18 “(4) The development of improved screening
19 techniques.

20 “(5) Clinical research for the development and
21 evaluation of new treatments, including new biologi-
22 cal agents.

23 “(6) Information and education programs for
24 health care professionals and the public.

1 “(d) AUTHORIZATION OF APPROPRIATIONS.—For the
2 purpose of carrying out this section, there are authorized
3 to be appropriated \$75,000,000 for fiscal year 2000, and
4 such sums as may be necessary for each of the fiscal years
5 2001 and 2002.”.

6 **TITLE II—DELIVERY OF**
7 **SERVICES REGARDING LUPUS**

8 **SEC. 201. ESTABLISHMENT OF PROGRAM OF GRANTS.**

9 (a) IN GENERAL.—The Secretary of Health and
10 Human Services shall in accordance with this title make
11 grants to provide for projects for the establishment, oper-
12 ation, and coordination of effective and cost-efficient sys-
13 tems for the delivery of essential services to individuals
14 with lupus and their families.

15 (b) RECIPIENTS OF GRANTS.—A grant under sub-
16 section (a) may be made to an entity only if the entity
17 is a public or nonprofit private entity, which may include
18 a State or local government; a public or nonprofit private
19 hospital, community-based organization, hospice, ambula-
20 tory care facility, community health center, migrant health
21 center, or homeless health center; or other appropriate
22 public or nonprofit private entity.

23 (c) CERTAIN ACTIVITIES.—Activities that the Sec-
24 retary may authorize for projects under subsection (a) in-
25 clude the following:

1 (1) Delivering or enhancing outpatient, ambula-
2 tory, and home-based health and support services,
3 including case management and comprehensive
4 treatment services, for individuals with lupus; and
5 delivering or enhancing support services for their
6 families.

7 (2) Delivering or enhancing inpatient care man-
8 agement services that prevent unnecessary hos-
9 pitalization or that expedite discharge, as medically
10 appropriate, from inpatient facilities of individuals
11 with lupus.

12 (3) Improving the quality, availability, and or-
13 ganization of health care and support services (in-
14 cluding transportation services, attendant care,
15 homemaker services, and day or respite care) for in-
16 dividuals with lupus and their families.

17 (4) Providing assistance to assure the continu-
18 ity of health insurance coverage for individuals with
19 lupus.

20 **SEC. 202. CERTAIN REQUIREMENTS.**

21 A grant may be made under section 201 only if the
22 applicant involved makes the following agreements:

23 (1) Not more than 5 percent of the grant will
24 be used for administration, accounting, reporting,
25 and program oversight functions.

1 (2) The grant will be used to supplement and
2 not supplant funds from other sources related to the
3 treatment of lupus.

4 (3) With respect to the imposition of charges
5 for the provision of services under the grant:

6 (A) In the case of an individual with an in-
7 come less than or equal to 100 percent of the
8 official poverty line, the applicant will not im-
9 pose a charge.

10 (B) In the case of an individual with an in-
11 come greater than 100 percent of the official
12 poverty line and not exceeding 200 percent of
13 such poverty line, the applicant will not impose
14 charges for any calendar year exceeding 5 per-
15 cent of the annual gross income of the individ-
16 ual involved.

17 (C) In the case of an individual with an in-
18 come greater than 200 percent of the official
19 poverty line and not exceeding 300 percent of
20 such poverty line, the applicant will not impose
21 charges for any calendar year exceeding 7 per-
22 cent of the annual gross income of the individ-
23 ual.

24 (D) In the case of an individual with an in-
25 come greater than 300 percent of the official

1 poverty line, the applicant will not impose
2 charges for any calendar year exceeding 10 per-
3 cent of the annual gross income of the individ-
4 ual.

5 (4) With respect to compliance with the agree-
6 ment made under paragraph (3), a grantee under
7 section 201(a) may, in the case of individuals sub-
8 ject to a charge for purposes of such paragraph—

9 (A) assess the amount of the charge in the
10 discretion of the grantee, including imposing
11 only a nominal charge for the provision of serv-
12 ices; and

13 (B) take into consideration the medical ex-
14 penses of individuals in assessing the amount of
15 the charge, subject to such provisions.

16 (5) The limitations established in paragraph (3)
17 regarding the imposition of charges for services ap-
18 plies to the annual aggregate of charges imposed for
19 such services, without regard to whether they are
20 characterized as enrollment fees, premiums,
21 deductibles, cost sharing, copayments, coinsurance,
22 or other charges.

23 (6) The grant will not be expended to make
24 payment for services authorized under section
25 201(a) to the extent that payment has been made,

1 or can reasonably be expected to be made, with re-
2 spect to such services—

3 (A) under any State compensation pro-
4 gram, under an insurance policy, or under any
5 Federal or State health benefits program; or

6 (B) by an entity that provides health serv-
7 ices on a prepaid basis.

8 (7) The applicant will, at each site at which the
9 applicant provides services under section 201(a),
10 post a conspicuous notice informing individuals who
11 receive the services of the policies that apply to the
12 applicant pursuant to paragraphs (3) through (6).

13 **SEC. 203. TECHNICAL ASSISTANCE.**

14 The Secretary may provide technical assistance to as-
15 sist entities in complying with the requirements of this
16 title in order to make such entities eligible to receive
17 grants under section 201.

18 **SEC. 204. DEFINITIONS.**

19 For purposes of this title:

20 (1) The term “official poverty line” means the
21 poverty line established by the Director of the Office
22 of Management and Budget and revised by the Sec-
23 retary in accordance with section 673(2) of the Om-
24 nibus Budget Reconciliation Act of 1981.

1 (2) The term “Secretary” means the Secretary
2 of Health and Human Services.

3 **SEC. 205. AUTHORIZATION OF APPROPRIATIONS.**

4 For the purpose of carrying out this title, there are
5 authorized to be appropriated \$75,000,000 for fiscal year
6 2000, and such sums as may be necessary for each of the
7 fiscal years 2001 through 2004.

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